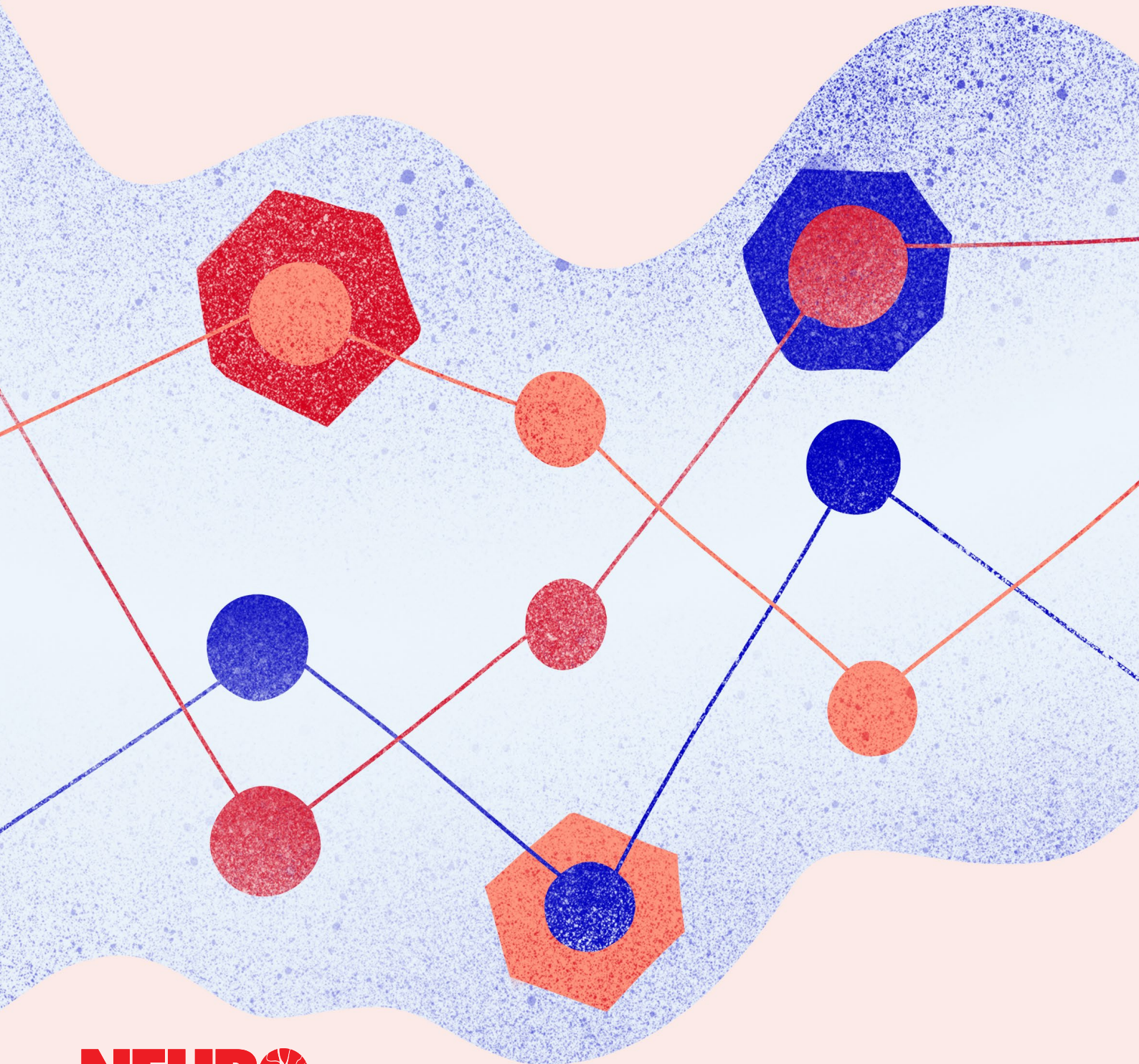


The Neuro report

2019

Summary



Intro

Large parts of the Neuro Report 2019 are based on our member survey, and this year we have asked questions pertaining to all of the areas covered in previous editions of the Neuro Report:

- **neurological care**
- **multi-disciplinary teams**
- **rehabilitation**
- **aids and assistive devices**
- **eHealth.**

The Neuro Report 2019 therefore deals with all of the areas for improvement that we have previously identified and written about.

In addition to these five areas, which we will come back to in this summary, we have also turned our attention in the Neuro Report 2019 to two other questions that are of great importance to our association; namely research and the role of close relatives. We have dedicated a complete chapter to each of these topics in the full report.

The report also includes a chapter on patient environment monitoring. This chapter reflects on the need for person-centric care and the transition that the Swedish healthcare system is on its way towards, where the primary care sector takes on a lot of the work traditionally done by hospitals. This is often referred to as the transition to what is known in Sweden as close-proximity care.

At the end of the report, we place our focus on the geographic inequality which is unfortunately a fact of life when it comes to neurological care and treatment. The report is also supported by six healthcare region appendices in which we discuss the differences existing at a national level based on the survey results.

Neuro provides funds for near-patient research.

1/2

Over half of the relative members who responded to Neuro's relative survey 2019 feel that they are in need of more support and/or information in their role.

Five identified areas for improvement

Neuro works to ensure that everyone diagnosed with a neurological disorder can receive the best possible level of care and treatment, adapted to their individual needs. With the help of our members, we have identified a number of factors that are key to good quality care and treatment and we believe there is a need for:

- **fast diagnoses**
- **multi-disciplinary teams**
- **rehabilitation using individual rehabilitation plans**
- **individually adapted aids and assistive devices**
- **the possibility for everyone to use eHealth services.**

It is our view that there is potential for improvement within all five of these different areas.



The diagnostic journey

What we refer to in this report as the diagnostic journey is everything that happens from the moment a patient first seeks care until they receive a diagnosis and adequate treatment, and it is something that we consider important to accelerate. There are a lot of good medicines and treatment methods available today that can slow down disease progression and prevent further functional impairments from occurring. The sooner these interventions are adopted, the better.

We consider that there is a need for:

- **doctors working within primary care to become more knowledgeable and aware of the symptoms that can indicate a neurological diagnosis**
 - Expand focus on neurology within medical training.
- **the general public to become more knowledgeable and aware of the symptoms that can indicate a neurological diagnosis**

- **the number of neurologists to be increased.**

In Sweden, the number of neurologists needs to be increased by a third (from 450 to 600 people).

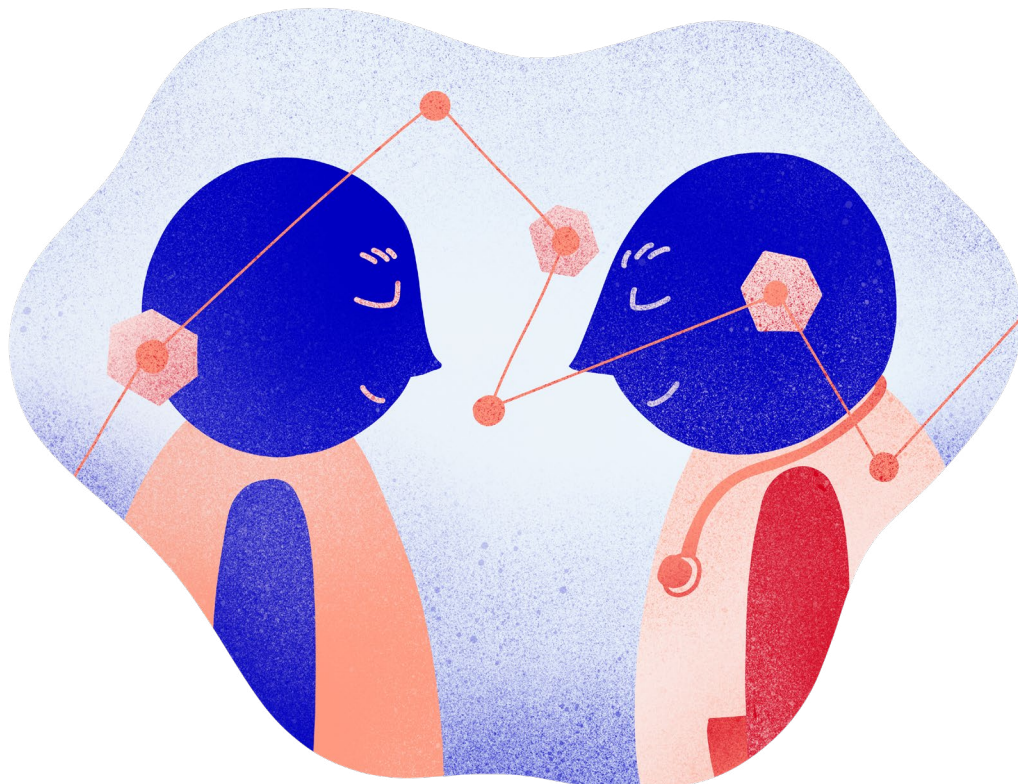
- Increase the number of outright residency positions within neurology (not combined with internal medicine).
- Introduce independent neurology clinics.

After receiving a diagnosis, it is important to ensure that patients are offered follow-up appointments with staff who have specialist competencies in the field of neurology. We therefore need a sufficiently high number of neurologists to meet this demand. Return appointments allow for further examinations and for the initiation and follow-up of treatment. Beyond obtaining a fast diagnosis, our members also consider it important that:

- **return appointments should also be covered by the national healthcare access guarantee.**

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Almost a third of patients have to wait over a year between first seeing a doctor and obtaining a diagnosis.



Multi-professional teams

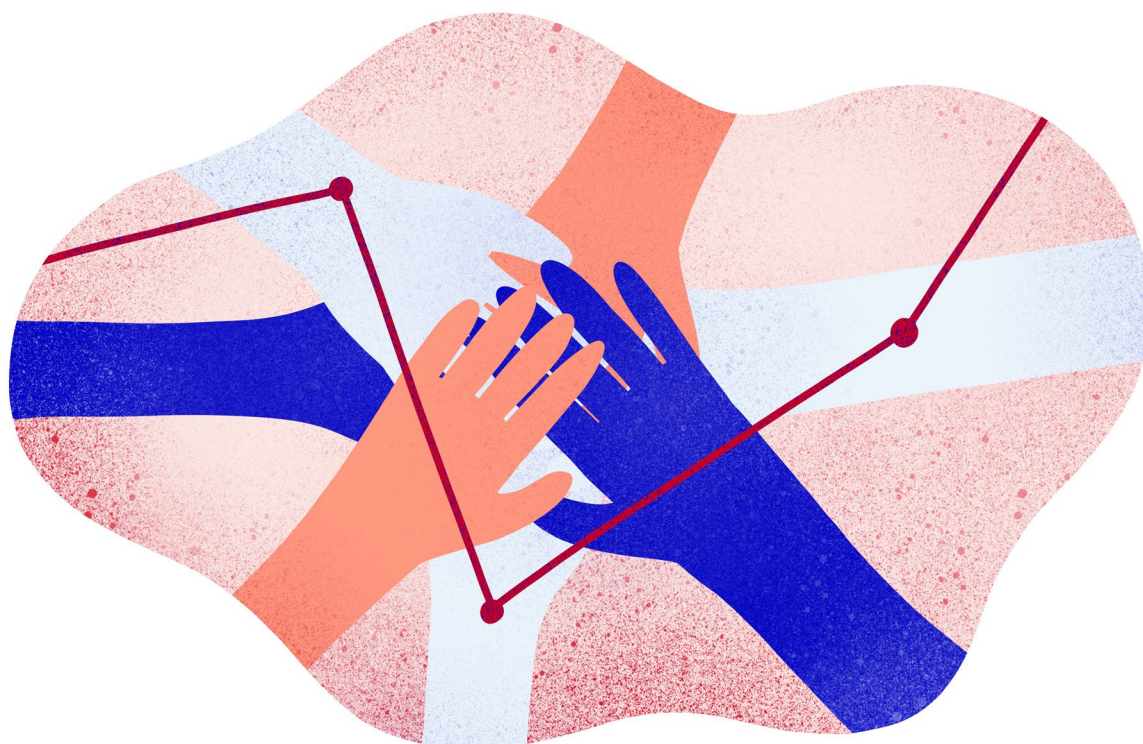
This refers to teamwork whereby several professional groups collaborate in an effective manner to meet the need for relevant healthcare in people with complex conditions, such as neurological diagnoses. This approach provides a good structure for follow-up care and allows different actors to coordinate so as not to unnecessarily burden patients and their relatives. Working in teams can also have positive effects on the competencies and working environments of healthcare professionals.

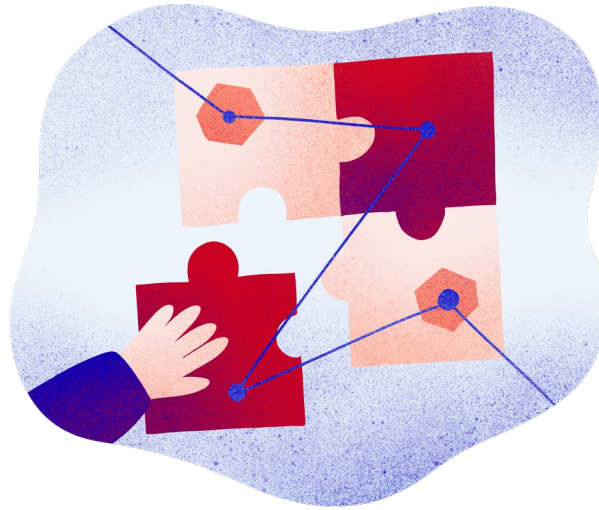
We consider that there is a need for:

- **the establishment of multi-professional teams around more individuals and for more diagnoses**
 - Access should not vary geographically, as it does now, depending on diagnosis.
 - Management should create a culture which allows different professional groups to learn from one another.
 - Medical record management and payment models should also be adapted to accommodate teamwork.
- **documentation around the value of team-based treatment and care**
 - There is a need for more scientific studies into the value for the patient of multi-professional teams within neurological care, in addition to socio-economic studies.

- **patients and their relatives to be given the chance to participate in teamwork**
 - Certain relatives should even be given individually adapted support and information about the care being given.
- **healthcare professionals to become more aware about the possibility of multiple diagnoses in a single patient and how these affect one another.**

Patients who have access to multi-professional teams are much more satisfied with the care that they receive for their neurological diagnoses.





Rehabilitation

Rehabilitation is important in terms of increasing quality of life for people with neurological diagnoses, preventing (further) functional impairments and enabling increased participation in work and social life. It is beneficial not just to the individual, but also to society at large in that the need for care is reduced and labour capacity is increased. Rehabilitation needs to be based around the needs and life situation of the individual and it is important that patients are actively involved in its planning. Patients need to be involved in the development of personal rehabilitation plans to be followed up on.

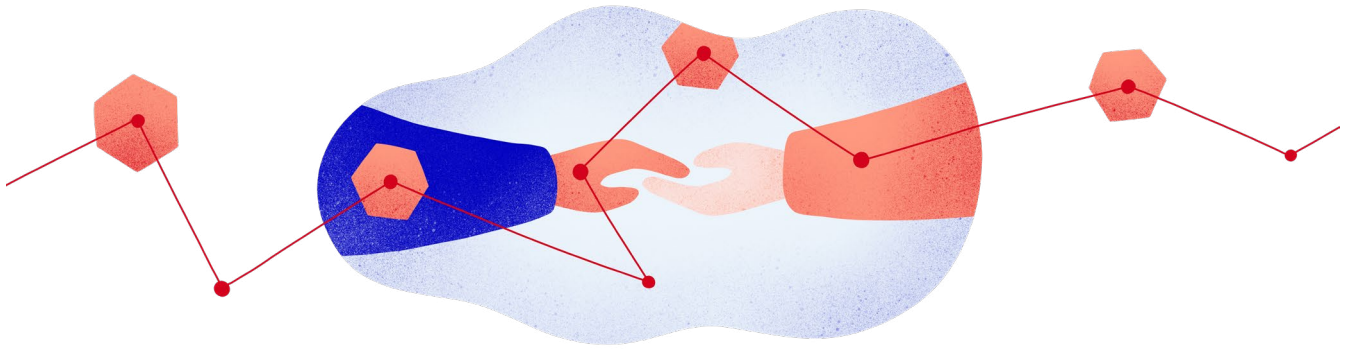
We consider that there is a need for:

- **rehabilitation to be given the same priority within the healthcare system as other forms of care and treatment**
- **better conditions for self-training**
 - In order for self-training to work in practice, patients must be offered accessible localities that work for people with mental fatigue, mobility problems and cognitive difficulties. Both the environment and equipment need to be suitably adapted.
 - Self-training is important and beneficial but must not be used as a complete replacement for rehabilitation led by trained specialists such as physiotherapists, occupational therapists, speech therapists or other healthcare professionals.
- **the government to launch an investigation into how effective and purposive rehabilitation and adult habilitation can be guaranteed for everyone with a neurological diagnosis all over the country**
 - Investigate with an aim to propose significant improvements. The investigation must address:
 - » overall demand and supply
 - » patient participation and quality assurance
 - » knowledge support for diagnoses and life situations
 - » responsibilities, boundaries and financing
 - » rights legislation.

- Initiate research and development work and learn from those patients who have helped to shape rehabilitation processes that meet their needs.
- **the guarantee of expertise within the area of rehabilitation**
 - It is paramount that we have a sufficient number of trained specialists within the various different healthcare professions.
 - Healthcare professionals must constantly be kept up to date with regards to things such as technological advancements within assistive devices and aids, etc.

1/3

Only a third of respondents consider that they receive sufficient information about rehabilitation.



Aids and assistive devices

Aids and assistive devices are often a fundamental prerequisite for a functioning every day life and participation in society. The term encompasses everything from hearing aids and walking frames (which are currently provided by assistive device centres) to kitchen equipment and furnishings (including those that can be purchased in ordinary stores) and IT-based aids such as smart phone applications, for example.

We consider that there is a need for:

- **the government to regulate access to aids and assistive devices through a rights law – with the possibility of appealing decisions – and to establish a suitable means of providing them to patients**
- **the provision of leisure aids in the same way as other assistive devices**
- **access to assistive devices to be facilitated**
 - Inform prospective users as to what aids and assistive devices are available.
 - Connect aids to the individual circumstances of patients and their overall need for aids and assistive devices and provide them to patients irrespective of their intended area of use (daily life/work/school/leisure activities).
 - Coordinate the supply of aids and assistive devices with other social services such as mobility transport, car allowances and home modifications in order to establish a single and functioning whole.
- **aids to be covered by the national healthcare access guarantee so that it will not take unnecessarily long for them to be supplied**
- **aids to be covered by a service guarantee that provides servicing and maintenance, including call-out services, servicing at home and in other places**
- **the following conditions to be secured:**
 - aids should be given a uniform and comprehensive definition
 - even short-term needs for aids should be taken into account within the healthcare system
 - access to aids should be equal on a national level
 - aids should be provided without entailing any additional costs for the user
 - aids should be included in individual care and rehabilitation plans
 - users should be actively involved in the prescription process
 - aids should be assessed on an individual basis and users should be offered supervised training in how to use them
 - choice of assistive device should be monitored, evaluated and reviewed on a continuous basis.

1/4

A fourth of respondents say they do not know if they have the assistive devices that they need.

E-hälsa

The government's *Vision for eHealth 2025* is without value unless we also have a vision for patients in order to ensure that everyone – not just those most in need – can make use of an expanded eHealth service offering.

We consider that there is a need for:

- **the government to introduce an eHealth reform targeted at patients**
 - Such a reform should include in-depth studies into different preconditions and needs.
- **patient participation to be secured in everything from innovation and development work through to individual patient initiatives**
- **the following conditions to be secured:**
 - targeted information that reaches patients
 - there must be no financial barriers to the use of eHealth services for any patients
 - availability of necessary technical equipment and support for all patients
 - individual adjustment as needed of both products and services such as technical equipment
 - training in how to use suitable products and services for all patients
 - eHealth services that are designed with a view to enhancing the personal healthcare contacts of patients
 - the ability to choose between eHealth services and human contacts.

People with neurological diagnoses can struggle with the Internet and therefore making use of the eHealth services being offered.

